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Introduction

AIDS remains a leading cause of mortality worldwide and is the primary cause of death in sub-Saharan Africa (UNAIDS/WHO 2007). Experiencing this epidemic first-hand are the children of those infected by AIDS, many of whom provide care and support for their parents or guardians. Care is often provided in difficult circumstances with inadequate access to antiretroviral drugs and palliative care services. With many children witnessing the slow disintegration of their parents' health and taking the role as the primary caregiver and head of house, it is perhaps no surprise that the circumstances of children living in households affected by AIDS have alarmed many academics, policy makers and mental health professionals. This is reflected by the growing body of literature on young caregiving and children of child-headed households in Africa. Whilst some of

this literature is reflective and provides a balanced account of the positive and negative outcomes of young caregiving, and acknowledges children as social actors, there is still a tendency to side with the dominant discourse in viewing caregiving children as victims in urgent need of psychological support.

It is the aim of this chapter to problematise any one-sided stereotype of caregiving children as passive and incompetent victims with solely detrimental experiences. To achieve this, I will first argue that this continued victimological focus on caregiving children is a result of dominant Western understandings of childhood and mental health. I will then give evidence to show how the psychosocial well-being of many caregiving children is rooted in a social context that draws on local understandings of childhood, which helps them participate in community life and build resilience.

My starting point is that children are social actors. I therefore locate this study within the 'new social studies of childhood', a paradigm which stands in contrast to the developmental psychology research that sees children as both dependent and 'becoming-adults' (James, Jenks & Prout 1998). However, to avoid simplifying the complexity and interdependence of children's livelihoods, I extend the argument that children's abilities to exercise agency and cope are dependent on the facilitating or constraining nature of their social environment (Abebe & Kjørholt 2009; Skovdal, Ogutu, Aoro & Campbell 2009).

In seeking to understand the psychosocial well-being of caregiving children, I have used the salutogenic orientation of Antonovsky (1987). Salutogenesis is an approach that allows public health professionals and researchers to examine social structures that foster coping and successful adaptation (Antonovsky 1987). This allows for possible explanations of how people cope with difficult circumstances. As an approach, it does not guarantee solutions to situations of hardship and the complex dynamics of human existence, but it does lead to a more profound understanding and knowledge of coping and well-being (Antonovsky 1987). As I seek to report on children's perspectives on existing indigenous coping strategies, developed by the children themselves within their immediate communities, this chapter contributes directly to research in the salutogenic tradition. I also argue that the best way to gain child-centred perspectives and develop culturally appropriate interventions is to draw on participatory action research methods.

Representations of Caregiving Children

> Being a young carer is portrayed in almost wholly negative terms in the literature (Olsen 1996, 44).

Research on caregiving children in the United Kingdom (UK) suggests that young caregiving can be a highly stressful situation. Experiences from the UK, for example, suggest that caregiving children often live in poverty and social exclusion (Dearden & Becker 2000), have emotional difficulties (Dearden & Becker 1995; 2004), and impaired mental health (Cree 2003). According to Aldridge and Becker (1993), caregiving children experience ill health and restricted opportunities for developing friendships and social networks, such as taking part in leisure activities, and have been identified to have limited visions of the future (Aldridge & Becker 1993; Dearden & Becker 2000) and difficulties with education (Dearden & Becker 2004). According to Olsen (1996), such research suggests that academics and health professionals are keen on addressing the ways in which caregiving children live, and are guided by an ideology of childhood as a period of protection, vulnerability and incompetence.

These UK-based perspectives have encouraged both researchers and policy makers to explore the circumstances of caregiving children in Africa (Robson & Ansell 2000). Development practitioners and policy specialists, for example, have already transferred UK-based representations of young caregiving to an African context. At an international symposium on 'young carers' in Nairobi (2006), practitioners, policy specialists and caregiving children from Africa and UK spent three days sharing knowledge on issues affecting caregiving children (Commonwealthtube 2007; TCSUK 2006). The conference was jointly organised by The Children's Society UK (TCSUK), who already facilitate a number of 'young carer' support activities and networks in the UK, and the Commonwealth Organisation for Social Work. The conference received much attention, including coverage on BBC World Service, covering the plight of caregiving children (Commonwealthtube 2007). In the BBC interview, Ruth Nesoba spoke of the problem of children taking on 'adult responsibilities' and of their 'lost childhoods'.

Literature searches on caregiving children and child-headed households in Africa yield only a small handful of papers and one book. These papers have

usefully mapped out the circumstances and problems faced by children living in households affected by AIDS. These include disruption of schooling, loss of friends and isolation, difficulties looking after an ailing person and the wider household, and trauma as a result of caring and bereavement (Ayieko 1997; Bauman *et al.* 2006; Donald & Clacherty 2005; Martin 2006; Robson, Ansell, Huber, Gould & van Blerk 2006; Ruiz-Casares 2007).

Work on caregiving children in Africa was initiated by Robson and her colleagues (cf. Robson 2000; Robson & Ansell 2000; Robson *et al.* 2006). In addition to looking at their circumstances and problems, Robson *et al.* (2006) also indicate the potential benefits of young caregiving, such as learning new skills, developing close and loving relationships with the person they care for, and growing up as a mature and responsible person. Donald and Clacherty (2005) have also helpfully noted the benefits and strengths of children living in child-headed households.

Guided by the initial observations of Robson and colleagues, Evans and Becker (2009) set out to compare the experiences of children caring for parents with HIV and AIDS in the UK and Tanzania. The authors draw on a resilience framework, providing a useful counterpart to a focus on risk and problems. Aside from identifying problems of stigma, poverty, poor physical and emotional health, social isolation and poor academic performance, Evans and Becker (2009) also identify the importance of supportive school environments, young people's friendships and supportive social networks. They conclude that researchers need to move away from a focus on the 'vulnerability' of caregiving children to one concerned with 'resilience' (*ibid.*). This is a good starting point to explore in greater detail the coping strategies, processes and resources that impact upon children's psychosocial well-being. Nevertheless, the perceived diversion away from 'normal childhood', which labels caregiving children as 'at risk', continues to give rise to psychopathological responses.

Childhood, Caregiving and Mental Health

The assumption that psychopathology is an appropriate framework for characterising African children with so-called 'adult responsibilities' as 'at risk' is

apparent. Researchers have consistently noted the psychosocial fragilities of caregiving children, highlighting their vulnerability to abuse (Ruiz-Casares 2007), depression (Bauman *et al.* 2006; Bauman, Johnson Silver, Berman & Gamble 2009; Boris *et al.* 2008), poor self-worth, unresolved grief, lack of long-term goals and poor internal locus of control (Donald & Clacherty 2005; Martin 2006), and lack of social support (Thurman *et al.* 2008). Similarly, guardian illness has been associated with increased risk of poor mental health among AIDS-orphaned children (Cluver, Gardner & Operario 2007).

In a comparative study of caregiving children in Zimbabwe and the United States (US), Bauman and colleagues (2006) investigated the psychological consequences of caring, measured in terms of depression. The very design of this study is permeated with victimological representations of caregiving children through its choice of a measure of 'depression' as the most appropriate tool to characterise their experiences. The study begins with the assumption that caring for an ill parent is an inherently traumatic experience, which automatically puts children at risk of mental health problems. Although the study found that 63% of Mutare children had clinically significant symptoms of depression, this was not correlated to caregiving (Bauman *et al.* 2006). Perhaps more importantly, they found the bond between child and parent to be an important predictor of child mental health. In fact, the study found that children may benefit from helping to make a parent feel better.

Whilst a minority of children undoubtedly suffer from mental ill health, it can be argued that the focus on children's poor mental health reflects Western discourses and representations of childhood as a period of innocence and psychological fragility in the absence of adult protection (cf. Summerfield 2000; Summerfield 2004). It is precisely such unproblematised associations and theoretical perspectives of caregiving children and child-headed-households that I seek to challenge in this chapter. Although attempts have been made to adapt and validate mental health measures in local contexts (Patel 1998; Pereira *et al.* 2007), the validity of diagnostic criteria for child disorders cross-culturally is still lacking (Canino & Alegria 2008). And whilst one can not ignore the increasingly sophisticated studies that give evidence to worrying trends of psychosocial distress amongst AIDS orphaned children (Cluver & Orkin 2009; Nyamukapa *et al.* 2008), it remains of concern that psychological frameworks

for the study of AIDS-affected children (e.g. Li *et al.* 2008) are based primarily on Western experiences, ignoring the experiences and life-worlds of children in Africa. As highlighted by Summerfield (2004), one very practical danger of Western conceptualisations of mental health and childhood is that the more prevalent Western and adult-centred theories and technologies in therapeutic treatment become, the more children (in Africa for example) will realise that they are not expected to cope using their own resources and networks.

It is therefore imperative that children living in households affected by AIDS are not seen as 'at risk' because of their deviation from Western and adult-centred representations of childhood, which are posited as the universal norm and neglect the historical and geographical specificity of children's experiences (Jenks 1992). Rather, children's vulnerabilities should be understood within their own social contexts. As Hutchby & Moran-Ellis argue (1998, 6), "Childhood is not a natural phenomenon or fixed stage of life, but a historically and culturally variable social construction." Psychosocial support is therefore best offered within a framework which seeks to recognise and boost social resources and existing coping strategies, with an understanding of the interplay between local representations of childhood and children's psychosocial well-being, rather than assuming that AIDS-affected children are automatically at risk of mental ill-health problems and typecasting them as 'helpless victims of Africa's problems'.

As a result of the developments described above, it seems sensible to focus future research on the psychosocial development and well-being of caregiving children. Euwema, de Graaff, de Jager and Kalksma-Van Lith (2008) note that such a focus automatically gives us an insight to their problems, but more importantly give us an insight to how the children, their extended families and communities cope with difficult circumstances. Equally important, a focus on well-being and coping also encourages us to move away from psychopathological measures (often developed by adults in the West) and explore, through participatory action research, the perspectives of the children on how they cope. Such a theoretical and methodological shift in focus could lead to the development of more meaningful interventions that could improve children's lives. This chapter presents a participatory action research project, in line with Freire (1996; 2005) and Lewin (1946), and gives an example of how a more dialogical

approach to research can help us reconceptualise the needs and circumstances of caregiving children and encourage more culturally relevant psychosocial support. To broaden the concept of caregiving children, I refer to 'young carers' as children under the age of 18 who provide significant nursing care and support for their sick, disabled or elderly relatives or guardians on a regular basis and play a key role in sustaining their household.

A Social Psychological Study of Caregiving Children in Western Kenya

To develop our understanding of young caregiving and to provide a more nuanced perspective, I set out to explore children's experiences and the perceptions they attach to their circumstances. Echoing Roberts (2008), I believe children are the real experts on their own lives and therefore draw on multiple methods (Photovoice, draw-and-write exercises with written reflections, and interviews) in an effort to involve and consult the children in the data collection process. The participatory research tools used in this study served as a catalyst for change, with the children's observations and recommendations being immediately translated into action through cash grants from a local NGO (WVP Kenya) catering for their material as well as psychosocial needs.

The information presented in this chapter is based on my analysis of data gathered from the first two phases of a larger ethnomethodological action research study. The study was conducted in the Bondo district of Nyanza province in Western Kenya in 2007. Bondo district was chosen for its high HIV prevalence rate, which is estimated to be 13.7%, still twice the national average (NACC 2005). Informants were sampled from two rural communities within Bondo district, both characterised by high HIV prevalence rates. With no known local definition of 'young carers', children who did more than 25 hours per week of work and care for an adult were purposefully recruited by local gatekeepers (committee members of a local community-based organisation) for this study. Forty-eight children aged between 12 and 17 years were selected from the two communities.

In consultation with the children, two Youth Community Clubs were established, one club in each community. The clubs continue to be facilitated and supported by social workers from WVP Kenya. Sports facilities, creative arts material and small cash grants are made available to the children through the clubs, with children meeting regularly for creative activities and to work on income generating activities such as growing kale, keeping poultry and selling maize. Data were collected through these clubs.

I distributed disposable cameras to all 48 children, but only 45 children managed to return their cameras for developing. Photovoice has been identified as a method through which marginalised groups can communicate, identify, represent, and enhance their community and circumstances (Stack, Magill & McDonagh 2004; Wang & Burris 1997). The children were briefed on the aims and objectives of the exercise, trained on how to take photos and briefed on the ethical implications of research and photography, such as the need for them to seek consent of those featured on the photographs and not to take photos of people in situations they thought would make them uncomfortable. In a brainstorming session, the children shared situations they thought would be inappropriate (e.g. of an ailing and bed-ridden adult to take pictures of). They were also given the option of drawing pictures of situations they wanted to share, but felt unsure about the appropriateness of taking a photo.

The children were told to pick six photos that had a relevant or important story they wanted to share and were encouraged to write reflections prompted by the following questions: 1) 'I want to share this photo because...', 2) 'What's the real story this photo tells?', and 3) 'How does this story relate to your life and/or the lives of people in your neighbourhood?' At this stage, if the children wanted to write about a situation that they did not capture on camera, they were encouraged to draw the situation. This exercise generated a total of 184 photos and 56 drawings, each with an accompanying written reflection or story. The Photovoice exercise was complemented with a draw-and-write exercise, covering the theme 'Caring for an adult'. The children were encouraged to make a drawing and write a short story or essay on the topic. These written assignments were further supported by 39 individual interviews and four group discussions with children as well as adults from the two communities.

To recognise and support the different ways in which children feel most able to share their experiences and perceptions of a phenomenon, a multi-method technique was used (O'Kane 2008). The use of multiple methods is a direct response to the hegemonic adult centredness of society and the disenfranchised position of children, which is often replicated in research involving children (Kirk 2007; Punch 2002).

All workshops and data collection were conducted in Dholuo language by two local research assistants and later translated into English. Interviews and written narratives were coded and analysed in Atlas.Ti using thematic networks analysis (cf. Attride-Stirling 2001; Skovdal *et al.* 2009). It is these thematic networks that will guide the remaining narrative of this chapter. The study was granted ethical approval by the Research Ethics Committee of the London School of Economics and permission to conduct the study was granted by the Department of Gender and Social Services in Kenya. Pseudonyms are used throughout to protect the identity the research participants.

To facilitate a re-conceptualisation of caregiving children, the findings presented in this chapter reflect the experiences of caregiving children and their perceptions of the impact of caregiving on their lives. I first provide some background to the social context in which caregiving children are located, which informs the possibilities and limitations on children's coping that are discussed later. I then explore the socioeconomic and psychosocial forces that determine a child's capacity to participate in social life. This is followed by an outline of what it means to be a caregiving child, including details of their roles and responsibilities and their needs and difficulties. The final section presents some of the strategies that caregiving children actively employ to cope with adversity, an engagement facilitated by local understandings of childhood and poverty.

Childhood, Young Caregiving and Poverty

To fully understand the caring experiences of these children, one must also develop an insight to the immediate context in which they are located. This

section presents some of the local understandings of childhood that influence representations of young caregiving. In doing so, this section does not seek to enter into a binary discussion on traditional versus Western notions of childhood, but seeks to argue that local understandings of childhood are vibrant and changing, influenced by disease, poverty and contemporary notions of childhood (Kesby, Gwanzura-Ottemoller & Chizororo 2006). It is within this framework that children derive meaning and access psychosocial support.

The sense people make of their surroundings often derives from social expectations and roles (Mead 1934). The traditional expectations of Luo children to contribute to the household economy, both formally through income generating activities and informally through their participation in home duties, is therefore an important observation. Luo children's contribution to livelihoods is part of every day life and language, with children being socialised from a very young age to take an active role in sustaining the household in which they live. One adult, for example, said, "a 10-year-old is old enough to know that he or she should help you with duties. The child can cook and arrange (working the farm) everything for the family to eat." However, this socialisation of 'working children' also reflects an adaptation to current problems of disease and poverty. One adult exemplifies this well, in her recognition of an increased likelihood that children will be left at an earlier age to fend for themselves due to death caused by AIDS and other tropical diseases.

> Once it was against Luo culture for a male child to go to a fire place, to cook in the kitchen. Today it has changed; they cook and do these duties. Also, if you don't teach him to cook and his wife dies, his children may suffer. Today you cannot know who will die first. (Adult4, interview)

Although the majority of adults argued that children should contribute to their household livelihoods, a minority of adults drew on more contemporary and conflicting expectations of children and said that children should be cared for, be in nursery and prepare for going to school. Nevertheless, many children continue to take on caregiving responsibilities. Most of the children involved in this study generated food and income through cultivation of their gardens and selling of their produce at a nearby marketplace. Sixteen-year-old Zeddy said, "I think it is important to grow vegetables; if one is assisting a sick person and has a garden, you can grow vegetables and sell them to get drugs to the

sick person, food and get money to buy clothes and shoes." In addition to contributing significantly to their households, caregiving children are also involved with much more intimate care such as bathing, massaging and feeding the sick. Reflecting on her experiences, one girl said.

> I was always with my mother at the hospital to ensure that when she woke up, a doctor would come and see her. I was washing her, washed her clothes, bought and brought her the drugs needed for treating her. I was doing everything for her in the hospital. My uncle came to pay the hospital bill. She was discharged, felt well but had no strength. (Catherine, age 14, Photovoice).

Although AIDS is arguably the root cause of much young caregiving, the prevailing notion of childhood as a time of duty and service, and the representation of children as 'helpers', has encouraged many parents to send their children away to provide care and support for ageing grandparents. In a group discussion, one adult said that "children can help in various ways, they can assist a grandmother, prepare porridge and wash her clothes. If I know she needs help, I will send my child and tell him or her to help the grandmother."

Children in this context respect their guardians tremendously and appear to draw on a number of sayings. The Luo saying '*chakochon loyo dhi ajuoga*' (a start in time saves nine), refers to how the destiny of a child is dependent on the teachings of its guardians. Reflecting such sayings, many caregiving children view their guardians as important and seek to live up to social expectations and responsibilities. One person who does that is 14-year-old Loyce, who in a Photovoice essay said, "I always help out my guardian and she always gives me food. My guardian gives good advice and is honest. I give her respect and live up to my responsibility all the time." By drawing on the representation of being a 'helper', many caregiving children see themselves as 'good children' and therefore often manage to see the positive side of caregiving. When reflecting upon her caregiving experiences, Everline, age 14, said, "people in the community love me, they are proud of me." Everline and many other young caregivers actively reflect on local representations and expectations of childhood, taking advantage of their responsibilities as 'helpers' and construct positive identities—a process that facilitates psychosocial coping and well-being.

These findings give some background to how disease, poverty and culture influence local representations of childhood and young caregiving. I have also briefly exemplified some of the activities caregiving children engage in, echoing findings made by Robson and colleagues (Robson 2000; Robson *et al.* 2006). In drawing on local representations of childhood, many of the caregiving children describe their circumstances gracefully and with little reference to negative consequences. I argue that the children's participation in community life, coupled with local representations, enable the children in this context to build positive caring identities that facilitate their psychosocial well-being. However, the responsibilities and experiences of the caregiving children do not come without challenges.

Needs and Difficulties Faced by Caregiving Children

Caregiving children face a number of difficulties and challenges. The challenges identified by the children fall into three categories. Firstly, poverty and destitution, including issues of malnutrition, access to water, material needs and poor housing. Secondly, psychosocial challenges such as lack of support, stigma, fear, bullying and parental bereavement. Finally, managing their education alongside caregiving duties.

As all the caregiving children participating in this study live in absolute poverty, their diet and nutritional intake is often inadequate. Many children made note of their undiversified diet compared to that of other children and families. For example, fifteen-year-old Carolyn notes that while other children "eat chapatti and beans, we eat *ugali* (cooked maize flour, a staple food). The following day they may eat something else, such as tea with rice, whilst we have *ugali* again." While poverty is a generic problem in Bondo, caregiving children do represent a minority and often describe their levels of poverty relative to other children. For instance, twelve-year-old Mercy said in an interview that "the difference between me and other children is that I go barefoot whilst they wear shoes, they have good clothes, they pay school fees on time, whilst I have to go and look for that money."

Other challenges faced by some of the children range from lacking social support, lack of time to play, experiencing parental bereavement, being worried about what the future might bring, and feelings of fear. Occasionally, caregiving children reported being bullied by other children and experienced abuse and neglect by adults, often as a result of the stigma attached to HIV/AIDS. Roseline, age 14, explained that she sometimes missed school, not because of her caregiving duties at home, but because "non-caring children talked badly about me. They joked about my mother's condition." Stigma attached to AIDS was also found to determine the level of social support available to some young caregivers. Whilst some children are without adequate support in their caring role, others, as I will show later, are much more successful in mobilising social support networks.

In general, all the participants attended school. Going to school served as an escape from their difficulties at home. Education takes up a large portion of their time and their commitment to education signifies the importance it plays in their lives. Education not only gives them a break from duties, but also provides them with an opportunity to spend time with friends. The children seemed generally satisfied with the quality of education and perceived education to be the only way out of poverty. However, managing their commitment to education with caring responsibilities was a challenge for many of the children. Some of the children therefore felt that their caring experience has negatively affected their school attendance and performance. As told by 15-year-old Debora, many children will, at some point, skip school to provide care for someone: "when my mother was sick I had to miss school, but had no permission to be out of school. The teachers did not understand my problem and caregiving duties. It was so painful for me to miss school." A number of children also mentioned their lack of concentration in school as a result of their worries and fears for their sick parents and what the future might bring. Although some caregiving children claim their school performance has persistently deteriorated since they took on caring responsibilities, many children go back to school and do exceptionally well.

> When the school re-opened I missed school; my fellow children were going to school as I stayed at home caring for my sister. I returned to school with only four weeks left. I told the teacher of my sister's sickness. The teacher

> encouraged me to study hard since I had missed a lot. I studied and managed to be position 9 out of 48; I performed well despite the fact that I only studied for 4 weeks out of the 14 weeks in a term. (Austine, age 14, Photovoice)

The ability of many caregiving children to bounce back and improve their school performance rank is an indicator of their resilience. Dropping out of school for a year to provide care for ailing or ageing guardians does not have to be detrimental to the child's school performance in the long-term. Although caregiving may come with a high cost at a particular point in time, some of which are highlighted in this section, their situation often improves. The challenges presented in this section reiterate that the children do face difficult circumstances and that these challenges should be addressed. Though the underlying causes of poverty and disease can be addressed at geopolitical level (Robson 2004), the challenges outlined in this section should also be addressed at a local and community level. The next section presents the social coping strategies of caregiving children, illustrating how children can negotiate and navigate social support by drawing on local representations of childhood.

Social Coping Strategies: Exercising Agency and Competence

To gain a more nuanced understanding of the lives of caregiving children, the background and difficulties presented above must be understood with reference to the children's social coping strategies. These strategies are located within a social context that allows children to exercise agency as they navigate and actively negotiate support. This section presents some of these processes.

In addition to the importance of education more generally, school and teachers are also an important source of support for some children. Twelve-year-old John stated that, "children can go to school and ask the teachers for support, who will see what they can do for the child." John expresses a confidence in the approachability of teachers and their capacity to help, and more importantly, he notes the active role of children seeking support by simply asking. Schools were reported as important for the children in developing friendships and in giving them a sense of normality and stability amidst difficult circumstances. Although schools have the potential to be supportive, an earlier example showed

how schools can also be a source of stress and unhappiness when caregiving and stigma impact on school performance and attendance.

Churches and faith-based groups were also mentioned by many children as a source of food and emotional support. A number of children took a photo of their local church, describing how their church had helped them with school materials, food and psychosocial support. The role of faith in helping these children cope is also noteworthy; many children believed that 'God gives answers and is always there' for them—providing them with tranquillity and hope. The faith and spiritual support from God was seen by some children to help them cope with bereavement and difficult circumstances.

Less fortunate and needy children also benefit more generally from community members. When asked about the potential sources of support for caregiving children, one adult answered, "If a child is living with an old person and struggling, I can buy him or her clothes because I know that s/he is suffering. It also means that if I do that, God will bless me." With many community members being willing to help vulnerable children, it is no surprise that many of the children reported neighbours and community members to be a source of support, particularly when it came to giving them food and school materials.

Accessing support from community members, however, rarely comes without some kind of negotiation. This negotiation ranges from the children giving generous community members an impression of their vulnerability in the hope this will gain them support, to them asking directly for support (with an awareness of whom to ask and when). Twelve-year-old Mercy drew on the former, describing the effect of wearing torn clothes, "some people buy you clothes because they see you wearing clothes which are torn. When they see you like this, the community/village can buy for you clothes with the money they have raised."

One of the dangers of this explicit negotiation is the victimological representation that the children contribute to. This is illustrated by 12-year-old Joyce who, in her negotiation for support, represented herself as a vulnerable child. She used clothes and physical appearance to project her vulnerability in order to receive support: "if we do not have clothes there may be others who can buy it for us. There are some parents who are very generous and when they see you hungry, they give you food."

Children were also found to project their needs explicitly to community members by verbally sharing their circumstances in the hope of winning sympathy that would translate into support. For most children however, negotiating support required a degree of reciprocity. Twelve-year-old Kevin illustrates this well by describing how he gets food from his neighbour, in return for his labour in weeding and harvesting their *shamba* (piece of land used for subsistence farming). By working their land and giving them some of the harvest, Kevin gets access to land and food that he otherwise would not have had. Kevin stated, "If I have no food, I get it from the neighbours and I assist them in harvesting maize, sorghum and beans." A more implicit strategy used by most of the children in conjunction with the less direct negotiation of support (as seen above), is to simply ask for support, as 15-year-old Carolyne would do, "The photo reminds me of the kind of support and love we get from the community members. If I need anything, I tell them and if it is available, I will get it."

Another more direct type of support usually takes place through a '*harambee*'. This is a Kenyan tradition of community self-help events, and translates into 'working together for a common purpose' in which vulnerable children receive support from groups or networks of community members. *Harambee* forms the foundation for the many community and grassroots groups that fill the social landscape in Bondo and support many children, irrespective of the stigma associated with AIDS. The strong community ethic and *harambee* which often makes support available to children during times of hardship also shapes the way in which the children themselves articulate a strong ethic of responsibility to care for those in need of support. Some children even set up groups and clubs aimed at helping one another. Inspired by what can be achieved as a group, 15-year-old Millicent said,

> I want to talk about this photo because these school children have formed a group which I am a part of. We help each other. I once had a problem and they helped me through a difficult time. They regularly came to visit my mother and they also helped me in fetching water and firewood. We should respect and assist one another. My fellow children help me. If a friend needs help we can always join hands and do fundraising to help someone through a difficult situation. (Millicent, age 15, Photovoice)

Bonds of friendship were also found to provide psychological support, giving the children someone to lean on emotionally during times of hardship. The strong notion of unity and togetherness (deriving from *harambee*) was often articulated as a route to success and survival. It was used as a means of coping through difficult circumstances and tasks.

Another important source of support is the extended and immediate family. From the extended family, males were more often found to contribute monetarily, whilst female family members more often visited the household and supported them with food and nursing care. The children who did benefit from their extended family network reported little negotiation with their extended family members in order to access support, reflecting a perceived obligation to help their own kin in times of need. Caregiving was often a shared responsibility between immediate family members, with siblings often assisting with day-to-day activities (such as cooking, fetching water and firewood). However, it is often the oldest child living at home who takes the role as head of house.

While responsibilities differ according to the circumstances present in each household, all the children in this study were found to contribute significantly to the wider household subsistence efforts, more often as part of a collective effort, with only a few doing so single-handedly. To cope with the lack of resources and food, boys and girls engaged in a variety of income-generating and farming activities. They sometimes had to negotiate access to land, animals and competitive market prices.

Most children reported on the importance of animals in generating food and income for various expenses. Thirteen-year-old Samuel took a photo of a cow that helps sustain his household: "I took this photo of a cow to show the benefits we get from it, like school fees, uniforms and money." By selling the milk, Samuel was able to cover some of his needs. Many caregiving children have not only their own needs in mind, but also those of their guardians. Animals were seen to help caregiving children diversify the diet within the household, and enabled them to purchase medicines and nutritious foods for their ailing guardians. This was expressed by 17-year-old Edith in a Photovoice essay, "if I am caring for a sick person and do not have money, I can sell a cow or the milk to get money to help with the treatment of the sick."

Cows, goats and chickens not only serve as important lifelines in sustaining the daily living of most caregiving children, but also give some of them hope for a brighter future when their animals reproduce and serve as insurance and an asset. The children fortunate to have livestock or fruit trees relied on them as insurance during times of hardship. In describing one of her photos, 13-year-old Susan said, "I love our goats and that is why I took the picture. These goats are important to me, they can help us when we don't have money, and we can sell them to get money for other things."

As this study took place in a rural area, the '*shamba*' (garden, piece of land used for farming) played an important role for all the children. The *shamba* enabled many children to grow vegetables and generate money through selling the produce. Nearly all the children made reference to the importance of fruit trees and vegetables in generating income, often with reference to how it helps them purchase school equipment and drugs for their ailing guardian. These activities illustrate their competencies in participating in activities that sustain them. The children were aware of their competencies and took great pride in their achievements, pointing out the value of being an active agent. Twelve-year-old Joyce, in reflecting on her active role in sustaining her livelihood, proudly said, "I feel happy because everything I have done will help me in future."

Although gender only played a small role in duties carried out at home, supplementary income-generating activities carried out in public places were highly gender-specific. Boys frequently engaged in the making and selling of charcoal (used for cooking), while girls offered more domestic services such as laundry and working in the garden for a small fee, typically to more affluent community members. Younger children, regardless of gender, typically fetched firewood and took it to the nearest market place for selling, contributing significantly to the daily income of their household.

What these findings indicate is that local understandings of childhood as a time of duty and service are materialised through the socialisation of children, and their active participation in sustaining their households, exacerbated by poverty and disease. As in many other rural African locations, this context encourages and recognises children who show agency and competence in engaging with resource generating or social support activities in order to cope with difficult circumstances.

Conclusion

The findings presented here suggest that many children are able to draw on a myriad of coping strategies and manage their difficult circumstances extraordinarily well. Many children manage not only to provide nursing care for their guardians, but also contribute to household economic survival through subsistence farming and income-generating activities. These findings are similar to observations made in Ethiopia (Abebe & Kjørholt 2009) and Tanzania (Porter 1996). The study also found that the children maintained and developed their psychosocial well-being by actively drawing on local understandings of childhood to participate in community life and make sense of their circumstances. These findings suggest that caregiving children are as active and competent as their social environments allow (Hutchby & Moran-Ellis 1998).

As a result, the children were able to actively navigate and negotiate social support. Within the immediate family, siblings share responsibilities; in turn, the extended family (such as uncles, aunts and grandparents) was often observed to provide support with money or food. Although support can be affected by stigma associated with AIDS and by poverty, assistance from community members and groups remains a critical coping mechanism. While women and home based care groups were mentioned, of particular interest to this study is the finding that children were also able to mobilise very effective friendship networks. Similar observations have been made elsewhere (Belle 1989; Berndt 1989; Nestmann & Hurrelmann 1994), however it remains an understudied phenomenon with children affected by AIDS.

In their study of the social representations of orphaned and vulnerable children in South Africa, Meintjies and Giese (2006) observe how the tendency towards framing orphan care and support policies and interventions within the framework of victimological Western representations of childhood (as a time of protection and play) could serve to undermine or displace local representations of childhood as a time of service and duty. Yet it is these very representations that enabled so many children in this study to cope with difficult circumstances.

What this study has argued is that the application of adult-centred theories and methodologies, often developed in the West, ignores some of more meaningful perspectives and processes that help us understand and promote

the psychosocial well-being of children living in households affected by AIDS. It is therefore critical that NGO workers and researchers working with caregiving children reconsider their tendency to universalise what are, in fact, their own very culturally specific assumptions about what should constitute a 'normal' childhood and mental health, and their tendency to implicitly or explicitly depict those that fall outside these assumptions as 'at risk'. To overcome this dilemma, I have shown that by using participatory learning and action techniques (cf. Freire 1996; Rifkin & Pridmore 2001), such as Photovoice and draw-and-write exercises within the framework of action research, one is able to derive more child-centred and culturally appropriate perspectives of how children cope and maintain their psychosocial well-being. Taking a child-centred approach, I have been able to document that many caregiving children, as a result of their enabling social context, are able to actively construct effective coping strategies and mobilise the social resources available to them, making it appropriate to view many of them as competent and active 'copers'.

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